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Cluster anxiety-related adverse events following immunization (AEFI): An assessment of reports detected in social media and those identified using an online search engine

Tiffany A. Suragh[a,*], **Smaragda Lamprianou**[b], **Noni E. MacDonald**[c], **Anagha R. Loharikar**[d], **Madhava R. Balakrishnan**[b], **Oleg Benes**[e], **Terri B. Hyde**[d], and **Michael M. McNeil**[a]

[a]Immunization Safety Office, Division of Healthcare Quality Promotion, National Center for Emerging and Zoonotic Infectious Diseases, Centers for Disease Control and Prevention, United States [b]World Health Organization, Headquarters, Geneva, Switzerland [c]Dalhousie University, Halifax, Nova Scotia, Canada [d]Global Immunization Division, Centers for Disease Control and Prevention, Atlanta, Georgia [e]World Health Organization, Regional Office for Europe, Copenhagen, Denmark

Abstract

Background: Adverse events following immunization (AEFI) arising from anxiety have rarely been reported as a cluster(s) in the setting of a mass vaccination program. Reports of clusters of anxiety-related AEFIs are understudied. Social media and the web may be a resource for public health investigators.

Methods: We searched Google and Facebook separately from Atlanta and Geneva to identify reports of cluster anxiety-related AEFIs. We reviewed a sample of reports summarizing year, country/setting, vaccine involved, patient symptoms, clinical management, and impact to vaccination programs.

Results: We found 39 reports referring to 18 unique cluster events. Some reports were only found based on the geographic location from where the search was performed. The most common vaccine implicated in reports was human papillomavirus (HPV) vaccine (48.7%). The majority of reports (97.4%) involved children and vaccination programs in school settings or as part of national vaccination campaigns. Five vaccination programs were reportedly halted because of

[*]Corresponding author at: Immunization Safety Office, Centers for Disease, Control and Prevention (CDC), 1600 Clifton Road, MS D-26, Atlanta, GA 30329, Georgia., Tsuragh@cdc.gov (T.A. Suragh).

Conflict of interest statement

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Statement

This paper contains original unpublished work and is not being submitted for publication elsewhere.

Disclaimer

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these cluster events. In this study, we identified 18 cluster events that were not published in traditional scientific peer-reviewed literature.

Conclusions: Social media and online search engines are useful resources for identifying reports of cluster anxiety-related AEFIs and the geographic location of the researcher is an important factor to consider when conducting these studies. Solely relying upon traditional peer-reviewed journals may seriously underestimate the occurrence of such cluster events.

Keywords

Anxiety-related reaction; Adverse event; Immunization; Vaccine safety

1. Introduction

Immunization anxiety-related reaction refers to an adverse event following immunization (AEFI) that arises from anxiety about the immunization [1]. Clusters of anxiety-related AEFIs have rarely been reported in traditional peer-reviewed journals and since 1992 there have been 8 published reports of AEFIs occurring in clusters or group settings [2]. These episodes may have serious consequences for both individual vaccinees and negatively impact vaccination programs. In certain instances, vaccinees have been misdiagnosed with anaphylaxis and/or other serious events resulting in hospitalization and/or medical interventions [3]. When these incidents occur in group settings, concerns about the safety of the vaccine may spread rapidly among vaccinated individuals and the broader community via print, television media, and word of mouth, which may serve to disrupt and possibly halt the vaccination program [4]. Reasons for why these events are not reported in the literature include a potential publication bias favoring reports in which the situation resolved and the vaccination program resumed [2]. There is also a need for evidence-based guidelines on how to prevent or address anxiety-related AEFI clusters occurring with vaccine introductions. Additional reports not previously found in the peer-reviewed literature can help to supplement the understanding and characterization of these disruptive events.

Social media and the web are becoming increasingly popular ways of sharing personal health-related information. Data sourced from these online networks may complement traditional information systems and assist public health monitoring and surveillance efforts. Although under-reporting may be expected to significantly impact the usefulness of such surveillance, in one published report, researchers found thousands of drug-related posts, potentially revealing serious and unknown Adverse Drug Reactions (ADRs) through data mining social media sites [5]. These methods represent new ways of conducting pharmacovigilance, and serve as an indication of how online surveillance systems can augment current systems [5]. The relatively small number of cluster AEFIs reported in the medical literature [2] leads us to suspect that the occurrence of these events are underestimated.

Millions of people use internet platforms to research and discuss vaccines, vaccine sentiments, and general public health issues [6,7]. There have been several studies looking at the role of online networks in identifying public attitudes toward vaccine safety [8–10]. These online networks may represent a novel resource for identifying potential clusters of

anxiety-related AEFIs and provide insight into how health issues are being communicated and shared over the Internet. We reviewed the Google and Facebook datasets due to their size and popularity among users. Google processes 100 billion searches per month [11] and Facebook connects over 1.5 billion people in over 80 different countries [12]. Forty-four percent of online users get news through Facebook and use the online network to discuss and disseminate information[13]. As a search engine, Google is able to index a variety of online report types (e.g., news websites, blogs, and academic websites) and this diversity in information is one of the strengths of this dataset and why it was chosen. Comparatively, Facebook offers a more exclusive online community (i.e., only members of Facebook can post, reply, and share information) and offers more insight into the personal opinions of individual users and how they interact with each other and share information. Facebook does not limit the amount of information that can be contained in a post, unlike other social media platforms like Twitter that limits the user's characters. We felt that more in depth information could be captured through Facebook as compared to other types of social media. However, there is potential in future investigation of all types of social media as each have their own strengths and insight into different online communities.

The primary objective of this exploratory study was to assess the possibility of detecting clusters of anxiety-related AEFIs, not otherwise reported in traditional peer-reviewed systems. The secondary objective was to explore the way clusters were being described online and shared by users.

2. Methods

2.1. Data

Two reviewers (one in Atlanta and the other in Geneva) independently searched Google and Facebook to identify reports (i.e., websites, blogs, etc.) of AEFI clusters (>=2 persons, following mass vaccination and concentrated in a geographic location or related to a primary cluster immunization event) (Fig. 1). Results were classified as those found in common (i.e., both reviewers identified the reports during their independent searches of Google or Facebook), and those found separately (i.e., reports found by only one reviewer based on the geographic location of where the search was performed). Google searches were done using the public search tool not private Google accounts, Facebook searches were done using private Facebook accounts and browser histories were not cleared. Reviewers noted if there were any changes to the search results that occurred when the searches were conducted on different dates and times. Each reviewer collected data separately and then compared results. Some reports described multiple events; for example, one report could describe 3 different cluster events. Likewise, there could be 3 reports (e.g., three different web-sites) referring to the same event. For this reason, we made note of not only the number of reports found, but also the number of unique cluster events. There were no date restrictions placed on the searches; however for feasibility as ours was a manual process, we limited our analysis to the first 3 pages in Google (i.e., 10 URL links per page) and the top 20 posts in Facebook. We used the following search terms: mass hysteria after vaccine, mystery illness after vaccine, fainting in school children after vaccine and mass fainting after vaccine. These search terms were developed following consultation with vaccine safety experts at the World

Health Organization (WHO) and the Centers for Disease Control and Prevention (CDC). We also pilot tested several search terms before choosing the aforementioned ones. Only reports in English were included in our analyses. Seven URL links identified clusters associated with journal publications in traditional peer-reviewed journals (i.e., URL links to the actual article not a description of the event by an online user) and were excluded from our analysis as they are already well described [2]. Therefore, we only analyzed reports found online not otherwise reported in scientific literature.

2.2. Analyses

We systematically reviewed reports and summarized patient demographics, vaccines involved, countries affected, public health response efforts, and any disruptions to vaccination programs. We also characterized the sentiment expressed in reports as positive, negative, or neutral regarding vaccines and vaccinations. Positive reports described the good safety profile of vaccines. Negative reports were skeptical of the safety of vaccines, vaccination policies, vaccine manufacturers, and/or public health officials. Neutral reports only provided details of the event. Reports where some parts of the report were neutral and some parts positive were considered neutral/positive. Reports where some parts of the report were neutral and some parts negative were considered neutral/negative. In both Google (when available) and Facebook, additional information was captured such as the number of likes, comments, and shares. All media reports were reviewed (TS and SL) and discrepancies were adjudicated by a third reviewer (MM). Two reviewers were used to limit reviewer bias, as the characterization of reports is somewhat subjective in nature. Descriptive data was compiled in a Microsoft Excel Spreadsheet. Results were characterized by those found in common or separately by reviewers, and also by their source (Google vs. Facebook).

3. Results

3.1. Reports found in common: Google

3.1.1. Demographics and vaccine type—We reviewed 120 URL links, with dates of events ranging from 2007 through 2016. From these URLs, 38 reports of cluster anxiety-related AEFIs were found in common by both reviewers (Table 1); these 38 reports referred to 17 unique events. The countries with the most reports included Colombia (13), United Kingdom (5), Pakistan (4), India (3) and United States of America (3). Most reports(47.4%) involved human papillomavirus (HPV) vaccine, followed by measles-containing vaccines (18.4%), and meningococcal vaccine (15.8%). The majority of reports (n = 37) involved children, with age ranging from infants to 17 years. The size of clusters ranged from 2 to 360 individuals. All reports either occurred in a school setting or as part of a state or national vaccination campaign and both sexes were affected. The most commonly reported AEFI was syncope (50.0%). Other common AEFIs included: dizziness, fatigue, headache, and tic disorders or involuntary movements (Table 1).

3.1.2. Outcome and management—In all reports, health officials immediately investigated theAEFIs, and concluded there was no link between the vaccine and the adverse

events. However, there were 5 cluster events where vaccination campaigns were halted (Table 1).

3.1.3. Tone of reports and additional information—Most reports (61.0%) expressed negative opinions. Of the 23negative reports, only 9 provided the name or some information about the author, while all of the positive reports (n = 5) listed the author's name. Four of the 10 neutral reports provided the author's name. Most of the comments left by readers were negative toward vaccination campaigns, vaccine manufacturers and public health officials.

3.2. Reports found in common: Facebook

All of the reports identified in Facebook referred to the same URL links (i.e., reports) identified through Google (Table 1); therefore, no new cluster events were identified through searching Face-book directly. We reviewed 80 posts, with dates of events, ranging from 2007 through 2016 and identified 18 reports of cluster anxiety-related AEFIs; however, 3 URL links were broken and could not be evaluated, therefore only 15 were included in our study.

Most reports (46.7%) were about the event in Colombia (2014) and the most common vaccine implicated was HPV vaccine(60.0%), followed by measles-containing vaccines (20.0%) and meningococcal vaccine (20.0%). All posts involved children, and for reports that included age, the range was 9–16 years old.

3.2.1. Tone of reports and additional information—Thirteen of 15 reports were negative and expressed distrust towards health policy makers and pharmaceutical companies. One report was characterized as neutral and one report expressed a tone that was considered to be neutral/positive. The number of comments ranged from 1 to 141 with the majority being negative. The number of shares ranged from 1 to 1,700 and number of likes from 1 to 1,600.

3.3. Reports found separately

Search results from Google and Facebook varied slightly depending on the geographical location of the reviewer and also the date and time the search was conducted (e.g., The researcher found different top 20 posts on Facebook in the AM of one day, than in the PM of the same day, and therefore searches had to be completed in one sitting). There was 1 additional report (referring to 1 event) of a cluster anxiety-related AEFI found separately by one reviewer and not the other. The report involved HPV vaccine, involved children and the size of cluster was 130 individuals, and expressed a negative view of vaccines (Table 2).

3.4. Themes expressed in reports

There were several repeating but opposing themes that emerged from qualitative analysis of the reports such as:

1. Vaccines are safe, widely used and are well studied:…… *Regardless, the vaccination, widely administered worldwide is safe… The health officials are also echoing assurances that the vaccine is safe, there is zero evidence that it causes adverse wide scale side effects…*" (*positive tone*)

2. Vaccines are harmful; distrust for public health investigators and pharmaceutical companies: "*The vaccine death cult is busy spreading its genocide in the South American country of Colombia, where young girls everywhere are reportedly falling ill with a "mystery illness" that their parents say is being triggered by the HPV vaccine Gardasil…*"(*negative tone*)

3. Genuine uncertainty as to the cause of the cluster AEFIs: "…*At present we are unclear regarding the reasons for the reaction to the vaccination and are completing an investigation with our immunisation colleagues…*"(*neutral tone*)

4. Discussion

As social media and the web become more popular and people increasingly share their health related experiences [14], it has proven to be a useful resource for identifying reports of cluster anxiety-related AEFIs not found in traditional peer-reviewed journals. In the United States, 61% of adults have looked for health or medical information on the Internet [15]. Additionally, 49% have accessed a website that provides information about a specific medical condition or problem [15]. According to a European Commission survey, 6 out of 10 European Union citizens go online when seeking health information [16]. Among the health information found on the web there can be reports of vaccine-related adverse events, including clusters, that are reported or blogged about. Reports of these clusters can be misleading in suggesting harm from vaccines which supports the importance of monitoring online sources. Our findings showed that most of the cluster anxiety-related AEFI reports occurred in children, usually in school settings, and affected both sexes. These findings are similar to the cluster AEFIs found in the peer-reviewed literature [2]. Five vaccination campaigns were reportedly halted in 4 countries, highlighting the potential negative impact that cluster anxiety-related AEFIs can have on vaccination programs. Given that these reportedly halted vaccination campaigns cover a broad range of countries (United Kingdom, Mexico, Romania, and Russia), it is imperative that more information be known, such as how each country responded and managed the outcome.

Our findings demonstrate the potential use of the web and social media as a supplementary information source(s) for AEFI surveillance. While ours was a labor-intensive process, our methods may be easily modified for capturing other types of adverse events and with an appropriate software application conducted as a semi-automatic process. With appropriate modification the potential value of public health disease tracking information resources and the possibility of including clusters of anxiety related reactions as a category or outcome may be helpful to detect real time posts of potential cluster AEFIs and that may be a useful tool for public health investigators.

We identified several key but opposing themes such as vaccines are safe and well-studied versus distrust towards public health investigators and pharmaceutical companies. The sentiment and the tone of communication of AEFI clusters may inform campaigns and other actions by public health agencies. It may be beneficial for public health officials to monitor the web and online social networks to better understand and address vaccine safety concerns and sentiments. By monitoring the web public health officials can try to counter

misinformation or negative information, with positive evidence-based data. Using lay terms and appropriate language similar to what is used by online users might help to facilitate more dialogue between online users and health officials [17]. Additionally, online reports or posts that express positive opinions of vaccines can be supplemented with evidence-based information (e.g., replying to these posts with positive language and additional evidence), which in turn might increase its online visibility. Overall, given the pace at which rumors may spread online and during times of crises when individuals tend to seek out information [18], it is imperative that public health agencies be alert to the sentiment and tone of discussions occurring in online forums and are prepared to respond effectively and rapidly to prevent or mitigate the spread of misinformation that might damage public trust and confidence in vaccines [19].

4.1. Google vs. Facebook

In regards to the search tools we used, Google as a search engine and Facebook as a social media platform with search capability, we identified the majority of our immunization cluster anxiety-related reports using Google. Google contained a greater variety of reports, including news websites, blogs, and URL links to scientific articles published in peer-reviewed journals. Facebook was primarily useful in providing additional insight among online users (e.g., how users interacted with each other via comments, likes, and shares). Many of the websites identified through Google included forums where users could post comments and interact with each other. Overall, Facebook had more negative reports (86.7%) than Google(61.5%). The reasons for this difference is unclear; it is possible that Facebook offers a more open environment for people to discuss their experiences or share their opinions [20 21]. Overall, Google provided more breadth of information (i.e., wider variety of sources of opinions), while Facebook provided more depth (i.e., more detailed personal stories, and interaction among users). Our study found 18 additional reports of cluster anxiety-related AEFIs than could be found in a systematic review of 18 years in the medical literature which only found 8 reports [2]. This study demonstrates that reviewing only traditional peer-reviewed journals may seriously underestimate the number of cluster anxiety-related events, the types of vaccines involved and associated clinical findings, and their impact on programs. Our data may be useful in developing guidance for immunization programs in preventing cluster anxiety-related events and mitigating their potential risk to vaccination campaigns, vaccine schedules and national vaccine strategies. It expands upon what is available from searching the traditional published literature and thus provides additional timely evidence and information on the impact of these events on public perception and acceptance of vaccines. However, the reports found online often lack details and specifics (e.g., vaccine type, symptom onset, clinical outcome and diagnosis) compared to reports described in the peer-reviewed literature. Therefore, online and social media reports may be regarded as indicators of real-time events and real-time posts, warranting further formal investigation by public health officials, or used to complement data found through traditional or current surveillance systems.

The limitations of searching the web and social media include the inability to examine entire social networks, which means that the fraction represented by our data of what actually exists is unknown. We are also limited to the information included in the online reports, with

potential biases and errors in reporting. Lastly, there was the challenge of conducting searches in different countries. The findings from our Google and Facebook searches were dependent upon the geographic location of the reviewer and this reflects targeting "popular" findings according to the search location and specific algorithms used by these companies. This limitation could have also been a result of our methodology, which only included reports found in the first 3 pages for Google and top 20 posts for Facebook. It is possible that if larger search samples (e.g., Google produced hundreds of thousands of URL links per search term) were analyzed, both reviewers would have found exactly the same results. Facebook results were dependent on the date and time of the search (e.g., the highest placed posts found on one day were not the same as those found the next day) therefore searches had to be completed in one sitting and some of the URL links identified in Facebook did not work. We used standardized search terms but other reports of cluster immunization AEFIs would likely be found by including additional search terms and expanding to different languages, countries and regions.

In conclusion, social media and online search engines are important sources for identifying reports of cluster anxiety-related AEFIs not found in traditional peer-reviewed journals. This exploratory study demonstrates the potential for using information from the web to supplement traditional systems. There is wide potential for future studies assessing other immunization anxiety-related reactions reported in other online networks, such as Twitter, Instagram, and YouTube. Additionally, studies in other languages and in more regions are needed to better understand the impact of immunization anxiety-related clusters globally. To assess how much this approach may improve the sensitivity of surveillance, a capture-recapture study would be needed. Social media reports may assist in informing public health officials of the adequacy of communication efforts concerning a cluster anxiety-related AEFI investigation and whether additional measures are needed.

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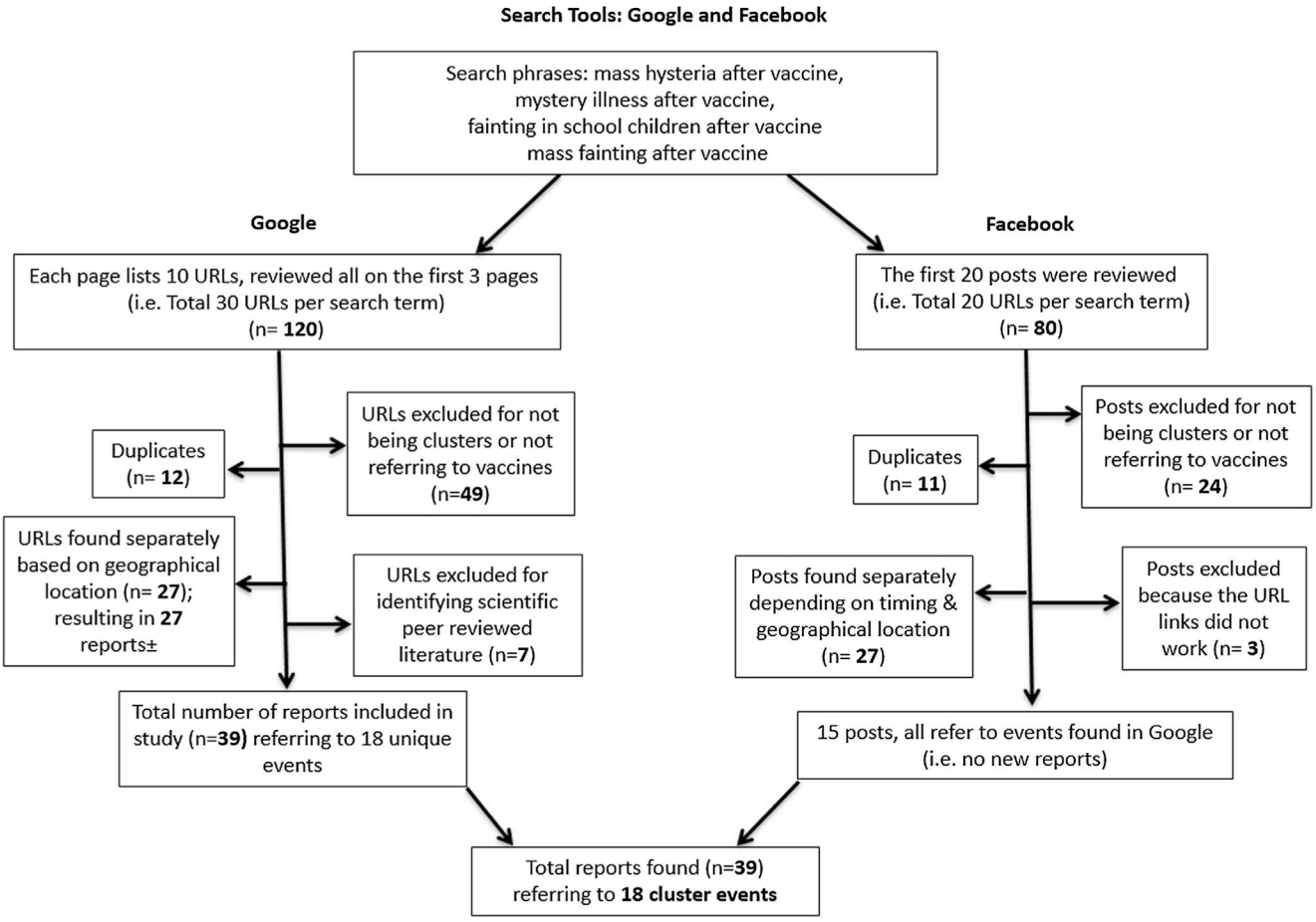

Fig.1.

Flow diagram of search tools.±26 of the 27 reports referred to events already found in common by reviewers, therefore only 1 report (referring to 1 unique event) was included in the final Google results.

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Table 1

Characteristics of 38 reports found in common by both reviewers.

Event	Date	Country (number of reports)	Vaccine (s)	Demographics	Common symptom (s)	Vaccine campaign halted (n = 5)	Source
1	**2016**	**United Kingdom (4)**	**Meningitis; not specified**	**10–15 high school boys**	**Fainting**	**Yes**	**Google; Facebook**
2	2015	Denmark (2)	Human Papillomavirus	3 girls	Dizziness; abdominal pain; nausea	No	Google; Facebook
3	2015	China (1)	Tetanus containing	360 children	Fever; breathing difficulties	No	Google
4	**2015**	**Mexico (1)**	**Tuberculosis; Hepatitis; Rotavirus**	**29 children; 2 infants**[±]	**“Illnesses”**	**Yes**	**Google**
5	2014	Colombia (13)	Human Papillomavirus	>200 girls; age 9–16 yrs	Nausea; dizziness; headaches	No	Google; Facebook
6	2014	Pakistan (4)	Measles containing	>95 school children	Fever; headache; nausea	No	Google; Facebook
7	2013	India(1)	Measles containing	6 school children	“Feeling restless”	No	Google; Facebook
8	2012	United States of America (2)	Human Papillomavirus	12–15 girls	Tic disorders	No	Google; Facebook
9	2012	Chad(l)	Meningitis	38 boys	Paralysis	No	Google; Facebook
10	**2012**	**Romania (1)**	**Tuberculosis**	**115 children**	**Swollen lymph nodes; abscesses**	**Yes**	**Google**
11	2011	India (2)	Tetanus containing; Polio; Unknown	45–61 children[≠]	Fever; pain	No	Google
12	**2011**	**Russia (1)**	**Vaccine against ticks; Meningitis**	**300 children**	**“Unusual behavior”**	**Yes**	**Google**
13	2010	China (1)	Measles containing	**17** infants[ϕ]	“Deterioration of sickness”	No	Google
14	2009	Sri Lanka (1)	Measles containing	**11** children	Headaches; vomiting	No	Google
15	**2009**	**UK (1)**	**Tetanus containing; Polio**	**7 school children**	**“Feeling unwell”**	**Yes**	**Google**
16	2007	Australia (1)	Human Papillomavirus	26 girls, 17 yrs	Paralysis; shaking	No	Google; Facebook
17	2007	United States of America (1)	Flu not specified	Male and female adults	Joint aches; pain	No	Google

[±]The children became ill and then 2 infants died later after getting the vaccine.

1st cluster: Over 50 children; 2nd cluster: 25 girls; 3rd cluster: 6 students; 4th cluster: 2 children died and dozen others ill after all receiving measles vaccine in similar timeframe.

[≠]1st report said 45 children, 2nd report said 61 children; this was part of a “Catch up campaign”.

[ϕ]The hospital said there were no adverse reactions in those infants after a consultation by doctors, however families said expired medication led to deterioration of children’s sickness and children were wrongly injected.

Table 2

Characteristics of 1 report found separately by reviewers.

Event	Date	Country (number of reports)	Vaccine (s)	Demographics	Common symptoms	Vaccine campaign halted	Source
1	2015	Ireland (1)	Human Papillomavirus (Gardasil)	130 teenage girls	Headache; seizure	No	Google